APPENDIX A: INTERVIEW TOOL

Interview Questions for Dying During the Pandemic: Family Experiences

The purpose of this study is to gain a deeper understanding of family members' experiences of their loved one's illness and death during COVID-19. During the interview we would like to explore how pandemic measures, use of technology, and the 3 Wishes Project may have impacted your experiences of your loved one's illness and death, as well as your own grief and bereavement. This interview is voluntary – there are no right or wrong answers. If there is a question that you would prefer not to answer please let me know. We are interested in understanding your experiences. Please feel free to share whatever seems relevant and important to you. If at any time, you need to take a break, or end the interview, please let me know.

The interview will be approximately 30-60 minutes in length. So that I can focus on our conversation and not have to take detailed notes, the interview will be audio-recorded and then transcribed verbatim to ensure that relevant information will be captured. (**If using Zoom, mention that we will not be recording video during the interview – just audio.) Before we begin, I just wanted to say how sorry I am about the loss of your loved one. Can you please tell me your relationship to (patient name) OR I understand that you were (her/his) (insert role/relationship), is that right? Can I ask what you called her/him?

1) Can you start by telling me about how you have been coping since then? (respond as appropriate)

Sub-question: Were you provided any information on bereavement services from the hospital?

2) Please tell me about your experiences as a family member of a very sick loved one during the pandemic? (probe regarding fear, anxiety, concerns about care loved on was receiving)

Prompt: What visiting rules were in place when your loved one was in hospital? Did the rules change over time? What was your experience with these visiting rules?

Sub-questions: What else was going on in your life around the time of loss? Were you working during this time, Did you feel involved in the decisions for your loved ones care?

- 3) In addition to the visiting rules, were there any other pandemic measures that affected the care of your loved one? (probe: issues with PPE, the ability to bring things to her/his room, issues with regards to travel for yourself or other family members)
- 4) How often were you able to connect with your loved one?

Prompt: Were you able to visit with your loved one in-person? If yes: can you tell me what the environment was like for your visits? Can you describe what you remember about the setting? What worked well? What didn't work well?

Prompt if mention is made of virtual visits: Did you visit with your loved one on the phone? On a video platform like FaceTime or Zoom? If yes: can you tell me what the environment was like for your visits? Can you describe what you remember about the setting? What worked well? What didn't work well? Is there anything you would suggest changing for future virtual visits?

Sub-question: In the event you were not allowed to visit, did the clinical team make efforts to have contact with you during your loved one's final days? If yes, how was that? If yes, how often? Contact with whom on the team? Is there anything that could have been done to improve this contact? If no, what would you have liked from the clinical team during your loved one's final days? What information would you have liked to have had?

Sub-question: Were you able to be present at the time of death? How were you present? What was that like?

- 5) Were there any sources of comfort either for you or your loved one during their last days? If yes, can you tell me about them? If no, is there anything specific that would have given them comfort?
- 6) Were you able to arrange a funeral or memorial service for your loved one?

If yes, what did that look like? Did the hospital offer any advice about services during the pandemic? Can you tell me about the experience of organizing and attending that service? What things, if any, were different because of the pandemic?

If no, are there plans to hold a service in the future?

- 7) It is always challenging to say goodbye to a loved one at the end of life. How did the pandemic protocols impact how you said goodbye to your loved one? How did you feel about this?
- 8) When your loved one was in hospital, are you aware of anything special that staff arranged for them?

If yes, could you give me some examples? How did those ideas come up? Who made them happen? Did you have the opportunity to suggest anything? Did these efforts influence your experience of your loved one's death? Did you ever hear about the 3 Wishes Project? If so, what did you learn about it?

If no, is there anything you think could have improved your experience with having your loved one die in hospital during the pandemic?

- 9) Is there anything else that you would like to tell me about your experience of having a loved one die in hospital during the pandemic?
- 10) Do you have any suggestions for the clinical team about caring for dying patients and their families during the pandemic or other times in the future when visiting restrictions are needed?

I would like to sincerely thank you for being so open and telling us about your experience as a family member of a hospitalized patient during the pandemic. Before we end the interview, I have a few demographic questions to ask you which will help us describe as a group, the family members who participated in our study. If you do not feel comfortable answering you can say no, or pass.

Participant Age:; Identified Gender:	; Religion:	: Ethnicity:	
Relationship to Deceased Patient:			

Thank you again for participating in this interview. END